Privacy & Security Tiger Team
Draft Transcript
July 6, 2010

Presentation

Judy Sparrow – Office of the National Coordinator – Executive Director
Good morning, everybody, and welcome to the Privacy and Security Tiger Team. This is a federal advisory committee, and there will be opportunity at the end of the meeting for the public to make comments. Let me do a quick roll call. Deven McGraw?

Deven McGraw - Center for Democracy & Technology – Director
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Paul Egerman?

Paul Egerman – eScription – CEO
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Latanya Sweeney? Gayle Harrell?

Gayle Harrell – Florida – Former State Legislator
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Carol Diamond or Josh Lemieux?

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Judy Faulkner?

Carl Dvorak – Epic Systems – EVP
She will be joining us shortly. This is Carl Dvorak on her behalf.

Judy Sparrow – Office of the National Coordinator – Executive Director
Hello, Carl. Good morning. David McCallie?

David McCallie – Cerner Corporation – Vice President of Medical Informatics
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
David Lansky? Dixie Baker?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Here.

<u>Judy Sparrow – Office of the National Coordinator – Executive Director</u>
Micky Tripathi? Neil Calman?

<u>Neil Calman - Institute for Family Health - President & Cofounder</u>
Here.

<u>Judy Sparrow – Office of the National Coordinator – Executive Director</u>
Rachel Block?

<u>Rachel Block – New York eHealth Collaborative – Executive Director</u>
Here.

<u>Judy Sparrow – Office of the National Coordinator – Executive Director</u>
Alice Brown for Christine Bechtel? John Houston?

<u>John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security</u>
Here.

<u>Judy Sparrow – Office of the National Coordinator – Executive Director</u>
Wes Rishel?

<u>Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst</u>
Here.

<u>Judy Sparrow – Office of the National Coordinator – Executive Director</u>
Joy Keeler?

<u>Joy Keeler – MITRE Corporation – Health IT Program Manager</u>
Here.

<u>Judy Sparrow – Office of the National Coordinator – Executive Director</u>
Adam Greene? Did I leave anybody off?

<u>Joy Pritts – ONC – Chief Privacy Officer</u>
Joy Pritts.

<u>Judy Sparrow – Office of the National Coordinator – Executive Director</u>
Joy, good morning. Sorry.

<u>Joy Pritts – ONC – Chief Privacy Officer</u>
Good morning.

<u>Judy Sparrow – Office of the National Coordinator – Executive Director</u>
You're way down the line here. Who else? Okay. I'll turn it over to Deven and Paul.

<u>Paul Egerman – eScription – CEO</u>
Good morning. This is Paul Egerman. I want to say good morning, and say this is very impressive to have so many participants at a 10:00 meeting after a 3-day weekend, so it's a huge dedication, so I thank

you for your dedication and certainly thank any members of the public who might be listening in, and belatedly want to wish everybody a Happy Independence Day.

To briefly review, the tiger team that we are a part of was formed for the purpose of getting some significant progress and rapid progress. There are a number of a privacy issues over the summer months, realizing that October 1st starts the eligibility period for meaningful use, and that there are also many activities that have already gotten started, and so there's a great sense of urgency to resolve a number of pragmatic issues. Our tiger team is made up people who are part of the policy committee and part of the standards committee and part of NCVHS, and so it's a diverse group of people. We report to the HIT policy committee. We had a meeting at the end of June. I think it was June 25th, and the policy committee actually accepted our first recommendations, although they made an interesting change that I'll review in a minute.

And so what we're going to be doing in today's agenda is we are going to be basically give you updates on the policy committee, on the consumer choice hearing, and also on Deven's presentation to the standards committee, and then we're going to be reviewing our schedule and agenda based on the more recent information from the policy committee. And before I start all that, I also have one administrative issue that I wanted to go through, which is since our June 22nd meeting, Deven and I received a letter from Paul Uhrig.

Deven McGraw - Center for Democracy & Technology – Director
Uhrig, yes.

Paul Egerman – eScription – CEO
Uhrig, who is the chief privacy officer and chief administrative officer at SureScripts who told us that we had a member of our team had made some inaccurate statements about SureScripts, and so I wanted to make sure that I mentioned that and apologize to SureScripts for saying something that was inaccurate. We are going to post a copy of the letter on the HHS Web site so everybody can see what was said. I did want to read one or two sentences from the letter that I think are very important that he said.

He says, ―And to be clear, SureScripts has never provided prescription or patient data (de-identified or not) to INS or any other similar entity. As a business associate of covered entities, we are subject to numerous contracts that restrict the use of prescription data."

Again, we'll post the entire letter, but I do want to apologize to SureScripts, people are SureScripts, an also perhaps the letter is a reason that we should caution the members of the team to be very careful when we talk about any specific entities because we do not want to accidentally create any misunderstanding.

Having gone through all of that, and also a comment I want to make to the people at SureScripts, I appreciate the fact that you listen to our public calls, and if you listen to the calls, or for anybody else who listens to the calls, and you think we've made mistakes or have any comments, we do have the time at the end of the meeting for public comment, and I hope that you will take advantage of that time period to make sure that we understand what is correct and give us any updates that you think are appropriate.

Having said that, I want to return quickly to the policy committee meeting that occurred on June 25th. Basically, at that meeting, unfortunately, Deven got stuck in airplane limbo on the West Coast, and so I ended up doing the presentation without Deven, although Joy Pritts provided me ample and able support through the process. What we did in that policy committee is we presented the two basic recommendations that we had made on message handling and on basically provider authentication, and we also described the NHIN Direct topic that was discussed at one of our meetings.

The discussion that occurred at the policy committee was very interesting on these issues. They accepted both of our recommendations. The change that they made to the recommendation really is very interesting and very significant. If you remember, the messaging handling recommendation had four categories. Categories A and B basically kept PHI, protected health information, encrypted. Category C and D had it unencrypted. And the recommendation included … best practices for directed exchange were found in models A and B where no unencrypted PHI is exposed or … the use of such models.

The sentence, ONC should encourage the use of such models, was the sentence that people wanted changed. There was a feeling that was very interesting. It was expressed notably by payers, this feeling that when intermediaries expose PHI, they're adding value in that process, that that value is very important, and that basically they did not want ONC to encourage the use of models that did not expose PHI, so they changed that sentence to, I don't know what the final wording is, but it'll be something like the privacy policies are simpler for models A and B, and so the basic implication is more complicated for the others, which are the ones that we will need to address.

That was interesting feedback and guidance that came from the policy committee. But all together it was certainly a successful situation, and I think the tiger team members should feel great about it. Deven, can you give us a quick update on the consumer consent in the standards committee?

Deven McGraw - Center for Democracy & Technology – Director
Sure. I'll start with standards committee first only because essentially what I did was to present the same set of recommendations, although I did talk to the standards committee about the discussion and essentially the removal of the sentence, ONC should encourage the use of models where there isn't unexposed PHI to an intermediary. And I think I wasn't at the policy committee meeting, but as I noted in the discussion with standards, I think there was the potential for that statement to be misconstrued, and so it has actually made it easier for me in presenting to the standards committee to have that sentence out because I think the set of recommendations were much clearer, A, that there are more privacy concerns raised when there is data exposed in the middle, but that in fact there might need to be an intermediary providing a range of services in certain circumstances. But as consistent with our recommendations, the least amount of data exposed necessary in order to fulfill whatever it is that is the business function that is being provided by an intermediary, if one is in fact being used, was certainly a consistent policy statement throughout.

I think the other – the standards committee was very interesting because there was also a fair amount of discussion that morning about NHIN Direct and the recently reached consensus set of standards and services that they're going to be pursuing, and I think we are going to hear some more, not in this meeting, but I think in subsequent meetings, from Arien and Doug to find out if there's more guidance that's needed in that respect. But it's not something that I think we're prepared to talk about today because we just haven't had, with the holiday weekend, a chance to circle back, but there certainly was that update provided there, and I updated the standards committee on our recommendations.

Now on the consent technology hearing, it was very interesting. We actually had very good attendance from our tiger team members. It was a long day, but it was a very informative day, and I think what we learned on that day is going to – I know what we learned on that day is going to be very instructive for when we get to the topic of consent and, in particular, consent at a more granular level based on type of sensitive data, for example. It was a very unique hearing in terms of its structure. There were presentations done by both users and vendors of some technology that has accommodated some level of granularity of consent, but I think we also got a clear picture of sort of the state of the technology in terms of both what its capacity is, as well as what its potential limitations are.

So we have the technology presentation, and then we had a reactor panel, which consisted of Dr. Deborah Peel, Melissa Goldstein, who is with GW University who was a coauthor of the ONC white paper on the issue of consent and is currently coauthoring their paper on data segmentation, Dr. David Kibby from the American Academy of Family Physicians, and also Jim Walker, who is the chief medical information officer at Geisinger Health Systems. I invited the reactors to send any subsequent thoughts they had to us after the meeting, and I have received e-mails from both Dr. Kibby and Dr. Walker, and I'll forward those to you, and if we receive anything else, we'll forward it along. But all of that, again, is going to be instructive for later discussions that we have on consent. I'll stop, see if there any comments from Paul and then other members of the tiger team who were likely in attendance or listening in on all three of the activities that we talked about.

Paul Egerman – eScription – CEO
Yes. The only other comment I had is when I presented to the policy committee, I did my best to make sure that I explained where there were … on a number of issues, so Latanya Sweeney had a viewpoint that I think is also shared by Carol Diamond that maybe you can't really do this where you really focus on policy for all technologies, and so we presented consensus, but we also presented, did our best to present that there were a number of other viewpoints, a number of issues. Is there anybody who has anything they want to add in terms of these update for policy or standards committee or for the consumer choice hearing?

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Are you looking for updates on content or impressions?

Paul Egerman – eScription – CEO
Did we capture it accurately? Is there something else that you have this impression that you think should be conveyed to the rest of the team?

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
I think that the panels made a strong case for progress in technological standards that might mediate consumer consent in an HIE environment and in an environment of connected HIEs, i.e. the NHIN. I do think that during the course of the day, we found both evidence of implementation of those standards and the recognition of a substantial amount of work that would be left before they would be practical on a national scale.

Paul Egerman – eScription – CEO
That's very helpful. Thanks. Does anybody have any other comments about the policy committee or the standards committee meetings? Do you think that that was an accurate description? Based on that, what has happened since the meetings is Deven, Joy, and I have gotten together and sort of worked a little bit on the entire schedule, and we thought it might be helpful to reset our schedule and our basic groundwork, the framework as to how we're going to operate going forward, so we have this PowerPoint presentation that I think we sent out to you in advance. We're going to walk you through, so make sure that everybody understands what we're trying to do.

First, in terms of where we are, the first bullet here is very important. It says we were formed to address privacy and security issues raised by ONC funded programs related to health information exchange, unless resolved over the summer. It's very important that you look at the phrase, "raised by ONC funded programs". One of the misunderstandings that we have seen is that some people seem to think that we're only involved with NHIN Direct projects. That's not the case. We're involved with a range of ONC funded projects, and NHIN Direct is one of them.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
This is John Houston. Can you just summarize briefly what all those might be just so we don't miss any? I apologize for asking that question, but I think it's important.

Paul Egerman – eScription – CEO
It's a great question. There's probably no human being who could summarize all of the programs.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
What about the…?

Paul Egerman – eScription – CEO
I think a lot of them probably relate to the various HIE organizations. I don't know if you want to call them HIOs that are funded where I think a lot of the questions are coming right now. I don't know if, Deven or Joy, you want to respond any further, if that's incorrect.

Deven McGraw - Center for Democracy & Technology – Director
Yes. I think there are two basic areas. One is the work going on to build the NHIN, so that would be the NHIN Direct project. That could be NHIN Exchange, maybe less so for NHIN Connect, which involves the federal health architecture, but there's that bucket, and then there's also the money that went out to states to facilitate health information exchange. That sort of cluster of issues for those state funded, for the programs that are state and federal funded, that hasn't received as much care and attention recently, but that also needs to be our focus.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
So it really sounds like any type of regional or national exchange almost becomes within the purview of this group simply because of either a direct or indirect relationship between our recommendations and what they're going to have to put in place.

Joy Pritts – ONC – Chief Privacy Officer
In particular, we have, ONC have been receiving requests, almost what I would say from the field or from our programs. In specific, the state HIE grantees had some issues that they have requested be addressed that they need to give guidance to the state, health information organizations or other means of exchange that are proposed in the state. And NHIN Direct has also come forward and said here are some of the issues that are coming up in our programs. We're trying to address those, but not to address them so much in a model specific basis, but pull back a level so that our – and I think we will go into this more as the agenda goes on here so that we have some kind of consistency across the potential methods of exchanging health information.

Gayle Harrell – Florida – Former State Legislator
This is Gayle.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
Joy, this is Carol.

Gayle Harrell – Florida – Former State Legislator
Deven, may I continue?

Deven McGraw - Center for Democracy & Technology – Director
Yes. Go ahead, Gayle, then Carol.

Gayle Harrell – Florida – Former State Legislator
Sure. We also have basically vendor exchanges. Do we have any – our policies and we are setting up and the framework that we hope to implement for privacy and security, will they have any impact other than perhaps being just a standard or best practice that's out there on vendor exchanges?

Paul Egerman – eScription – CEO
This is Paul responding, but the way I look at it is when we make our privacy recommendations that are accepted by ONC, it applies to everybody, including the vendor exchanges.

Deven McGraw - Center for Democracy & Technology – Director
Yes, I would agree with that, and particularly for each of – when we make recommendations, we should always be mindful. I feel like I'm channeling John Houston here about how we expect to hold people accountable for complying with them.

Paul Egerman – eScription – CEO
That's right. We're going to get to that issue in a minute, but your question is a good one, Gayle, but it's basically even though the questions may be coming from the funded programs, they apply to everybody, whether it's the funded programs or vendor….

Gayle Harrell – Florida – Former State Legislator
Yes. It sounded like it was just funded programs. Certainly the states are receiving large amounts of money. The designated entities will be getting a good amount, and it will funnel down to the regional HIOs or whatever. But you also have other private kinds of exchanges going on out there, and they also need to be held accountable.

Deven McGraw - Center for Democracy & Technology – Director
Yes.

Paul Egerman – eScription – CEO
Absolutely.

Deven McGraw - Center for Democracy & Technology – Director
Thanks. Carol?

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
Yes. Joy, just a question on your comment. I'm wondering what you mean when you say specific kinds of models like NHIN Direct. From my perspective, NHIN Direct, NHIN Connect, NHIN Exchange, I don't think it really matters. I think any time you have a policy discussion about any of those, you're talking about policies for information sharing. And I'm just wondering what it is about NHIN Direct that you feel is very specific from a model perspective that distinguishes it from the others. It may in fact be the states use NHIN Direct or they use NHIN Exchange or that vendors use NHIN Direct or NHIN Exchange. I don't think we know. I guess I'm just wondering what specifically you're referring to when you say that that's a specific model.

Joy Pritts – ONC – Chief Privacy Officer
I wasn't really referring to NHIN Direct as a specific model. I was referring to it as a specific program that brought forward issues that they wanted to have addressed, and we believe that many of the policy

recommendations, in fact, most of the policy recommendations that will come out of the tiger team should be applicable no matter what type of exchange is involved, but there will be some times of exchange that involve issues that aren't present in other methods. For example, a query and response model may raise issues that are different than what has been called, although I know that technologically this is not the accurate term, but people in this group have been calling it a push model. I would call it a solely provider initiated model. So it's not a query and response model. It's a slightly different model. There will be things that occur that are not uniform that may need to be addressed.

Paul Egerman – eScription – CEO

Those are all important comments. Later in this presentation, we'll go through a description of what the models are, and I agree with what Joy said. NHIN Direct is not a model. It's more of a transport standard. But I could continue on because one of the things that Deven and I have resolved to do is to do a much better job of dealing with the agenda, and I'm on the very first bullet of slide number two. Slide number one was the title, so I need to … I could get a little further alone.

The first thing was the description of who we are, and it's appropriate we had a discussion about this. The main point is that it's not just NHIN Direct. We're working on a broad basis that affects both the ONC funded programs and the vendor programs, although we're using really feedback from the ONC funded programs to help direct our work.

The second bullet, as you know, we did do one set of issues from the NHIN Direct project that was successful. The third bullet that's on the screen that's also really very important to mention is, we really very much appreciate the time that you, the members of the tiger team, are spending on this. We're having meetings twice a week. People are flying to D.C. before long holiday weekends, and the level of commitment is really very exciting. Joy once made a comment that people, we said if you can get the right group of people in the room for a period of time, they could solve all of these issues. I really do think we have the right group of people in this tiger team that we have, as it says in the fourth bullet, a lot of work to do and a short period of time to do it.

I want to introduce the next set of topics that we will be addressing, and again, a lot of this did come from information from the state health information organizations. And so there's this list of pockets that we need to address. The first one that we're going to talk some more about today, collection, use, and disclosure limits, which includes the parenthetical comment, data reuse and retention. The second is consumer choice and consent. Following up on that is the issue of sensitive data, which includes a discussion of data segmentation. We also have a bullet on provider services, and we actually got started on that when we started talking about basically trust models and who is going to issue certificates for providers.

There are some other issues that are listed here: authentication, identity assurance, but there are also issues related to provider directories that we have to discuss. The next issue, a very interesting issue, is patient identification matching, in other words, how do you match up to make sure you've got the right patient when you have two different organizations talking and may have different numbering systems to identify those patients. Finally, NHIN governance, including accountability and enforcement, we will be addressing that issue.

Now that is a lot of stuff, and we want to do almost all of that, believe it or not, this summer. I'm going to tell you in a minute what the schedule is. But in doing that, when we worked out the schedule, we didn't get everything done, and so we actually put in a parking lot of some issues that we just couldn't see ourselves getting done, say, by September. And these are the issues we have on what we call the parking lot. It'd be great if we could somehow wrap up all those other issues I just showed you and do these three, but we just felt we couldn't do everything, and so we took some issues and said, we'll leave that for the fall.

The first one is patient issues. It's really patient access issues. How do patients access systems? How do you do identity assurance of patients? How do they do the corrections?

The second issue, is the de-identified data, which has … this is a very interesting issue, but it has its own set of issues. And the third issue is what are the basic rules for intrastate exchange, the exchange between states. Let me pause there.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Yes. This is John Houston again. Regarding your last slide with regard to sensitive data, NCVHS is looking for the September timeframe to be putting out some recommendations related to sensitive data types, which I think will help in many ways with regards to your third bullet. I don't know if it would make sense for you to maybe put that on the parking lot knowing that we're doing that work, and that whatever other stuff needs to be done related to that, you might want to do after we make those recommendations.

Paul Egerman – eScription – CEO
Right, although that could be, although the observation I would make is when you see the schedule, we're approaching sensitive data from a standpoint of consumer choice, in other words, how consumers have choices about sensitive data. It could be that we could address that somewhat independently of what it sounds like you all are doing, which is really defining what are the sensitive data elements.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Yes. Because I notice you broke out consumer choice and consent separately than sensitive data.

Paul Egerman – eScription – CEO
Yes, although that's not quite – that's correct, which is a good observation, but I think they're really approaching it primarily from a consumer choice standpoint, which you'll see, I think, well, maybe not. Do you agree with that, Deven?

Deven McGraw - Center for Democracy & Technology – Director
Yes. I think we are. John, we should have a conversation to be really clear about what the scope of your September letter, what you think you guys are going to cover at NCVHS, so we're leaving room for that because we don't want to step on that, and there are plenty of issues to tackle, and best if we sort of divide and conquer rather than each doing the same thing. So I think my impression, I think Paul and I are in agreement that we were looking at it from an individual consent perspective, and that's an issue that you guys have already weighed in on.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Right.

Deven McGraw - Center for Democracy & Technology – Director
And that we will be incorporating that letter that you all wrote to HHS on sensitive data, I think, in our discussions.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Let me give you the 60-second view of what we're doing with NCVHS because it really is intended to be very narrowly drawn to make sure we get a letter out in September, but it was really to try to put together our recommendations on what are the sensitive data classifications. For each classification of date, what

are the specific considerations? What really does fall within that sensitive data class and what falls outside of it, and make some recommendations as to what information we really think also needs to be shared and in what context. So we really wanted to try to limit our focus so that we could get a letter out in September. Again, I think it does, based upon your description, does fall in line, I think, with what you're trying to do.

Deven McGraw - Center for Democracy & Technology – Director
Okay.

Paul Egerman – eScription – CEO
Sounds good. I appreciate that, John. Moving on….

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Paul, this is Dixie Baker. I have one question about that last slide, the parking lot slide. We mean by de-identified data as defined in HIPAA, right?

Deven McGraw - Center for Democracy & Technology – Director
Yes.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
So we will be addressing a lot of HIEs and users of data, call data de-identified, even when it's just the names removed, so that part we'll address, but just not the, if you de-identify it according to HIPAA, then it's on the parking lot.

Deven McGraw - Center for Democracy & Technology – Director
I don't think we can speak to what people call de-identified data and isn't de-identified data. I think, for our purposes, to remain focused, there's PHI, and then there's data that's de-identified, and data that's de-identified must meet the HIPAA standard in order to be de-identified. Otherwise it's PHI.

Paul Egerman – eScription – CEO
That's correct.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Got it. Thank you.

Rachel Block – New York eHealth Collaborative – Executive Director
This is Rachel. I have one other sort of clarification just in terms of buckets here. In the topics that we proposed to address next, you've got NHIN governance, and I know that's a little bit later in the timetable here, but then parking lot, we've got interstate exchange and the authentication and some of the other things. But aren't those, to a certain extent, intertwined? Question number one is, aren't those somewhat intertwined with NHIN governance? In other words, how do we separate those two things out?

The other comment I would make is that the Office of the National Coordinator is, I would say, encouraging is probably not quite strong enough of a word, all of the state HIEs to engage in interstate data exchange as a priority activity under our HIE grants. So I'm just a little concerned about what it means to put that issue on the parking lot if we're going to be expected to address that sooner rather than later in the context of the state grant programs.

Joy Pritts – ONC – Chief Privacy Officer

This is Joy. I'd like to field that one a little bit. We are keenly aware that, first of all, almost every item that will be discussed by the tiger team probably is incorporated into the overall governance topic in general. If you were at the standards or the policy committee meetings, there is a plan to issue. I believe it's a request for information on NHIN governance, and that is the context, I believe, in which this group will be asked to address that topic as an overarching principle as opposed to these individual components that we are looking at right now.

The interstate exchange issue is, of course, important, but so are all these other items that we have also been asked by the state HIE program to address. So with the limited resources we had, these were the items that kind of bubbled to the top, and so they are the ones that were assigned the top priority. I'm looking at these, and I'm not sure how. I know that there is some work going on with the DURSA, which impacts the interstate exchange, but it's not being addressed through this workgroup, so there are other forums where interstate exchange is actually being addressed, but it's not here.

Rachel Block – New York eHealth Collaborative – Executive Director
Okay. I'll just say, from my perspective as a tiger team meeting, that doesn't make any sense to me. I'll just express that, and I'll move on.

Paul Egerman – eScription – CEO
I appreciate that, Rachel, but let me address what you just said in the context of the next slide where we have a proposed schedule for our work, and basically what we tried to do is we tried to lay out the topics for all of July and all of August as to what we're going to do. If you look at today's meeting, July 6th, it's framing. July 9th, which is Friday's meeting, we have collection, use, and disclosure, which we're going to talk a little bit more about in a minute.

And then next week, the 13th and 16th, is to hopefully wrap up some issues related to consent, so that on July 21st, we'll similarly have some recommendations to present to the policy committee. July 23rd … sensitive data, and you get the provider services. Then you see August 11th and August 16th, on August 11th, we have an open slot. On August 16th, we actually have a total review of all the decisions made. So the purpose of the total review is to look at everything as a whole to see if it all makes sense. But also having an open part of the schedule on August 11th, we thought that that could be done for used for two purposes. One is if we didn't quite make the schedule, and we had some issues that we needed more discussion on, we could use that. But the flipside is for suggestions that you're making, Rachel, that you maybe really like to get started on some of these issues with interstate exchange or if there are other issues relating to even perhaps some of the de-identification data or if there are other issues related to NHIN governance. If we can operate according to schedule, there could be an opening in the schedule to bring in some of those issues and address them, and so that would be partly how I would respond to your question, Rachel, because it's a valid question. It's hard to do this thing piecemeal, but it's also hard to do this thing if you don't look at it in individual chunks.

The schedule also is intended to answer the question that Judy Faulkner asked early on. She wanted to know when we were going to be talking about what subjects, and so we do have a plan, and so this is what we're going to be trying to do. In looking at this, it's a slight variation of what we had talked about previously, so you see this on the next slide. Instead of talking about an entire model and every aspect of the model, what we're going to be doing is sort of looking at each topic or question, and I don't know how to describe it. It's like vertically versus horizontally. Horizontally … for our next topic is data reuse and retention. And then we'll be making recommendations about that, and those recommendations will be different for the directed exchange model, for the federated model, and for the centralized model, so we'll make specific recommendations for each model for each topic. As you see down at the last bullets, we will use the privacy and security framework that already exists to help frame and define issues. In other words, wherever we can, we should be building on to the existing material.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
This is Carol. I just want to express that this construct makes no sense to me because each one of these models makes many policy determinations, and I just, I'm really struggling with how this can work for each of the policy areas when each one of the – in other words, I think this kind of separation of this is the technical approach, and now we have to come up with policy really limits the understanding that technology does make policy, that architectural and technical choices are making policy all the way along, and that policy should not be made in response to that, but rather in cooperation with that.

Gayle Harrell – Florida – Former State Legislator
I'd like to reiterate also that there are other models out there. Currently we have some HIEs that are using a hybrid model between the federated and the centralized model, and if you put things in boxes, it becomes very difficult when you have models out there that don't fit in the box.

Deven McGraw - Center for Democracy & Technology – Director
Yes. I don't know that we want to create a separate set of recommendations per model. I think we have a set of recommendations, but as Joy mentioned in the beginning of our call today, there may be some particular issues that need to be addressed that are raised by a model that's out there that needs a particular set of policy considerations. I don't disagree that it would be ideal if we were starting from scratch, but in some respects, we're creating policy in order to answer to a set of circumstances that are already out there in states and models for which states have already begun to invest resources. And so unless I'm told by ONC that they're going to be model selecting and, therefore, we actually can have a conversation where we have a set of policies and a recommended set of technology choices in order to advance those policies, I think we, to some extent, set the right policy, but we cannot avoid thinking about how that might apply to the models that we know exist out there today.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
This is Wes. I'd like to add that I believe most operational HIEs today, and certainly most of the plans that I've seen, are in some sense hybrids.

Deven McGraw - Center for Democracy & Technology – Director
Yes.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
And it may be useful to take a set of policies and make comments about how they apply to those aspects of the work of an HIE that might be described by this abstract model. It really would make no sense at all to partition our recommendations that way. But peaking ahead at the slides, I think that's what our plan is. Right, Paul?

Paul Egerman – eScription – CEO
Yes. That's correct, Wes. I appreciate the comments. The comment is a valuable comment. Yes, we're not going to really partition it for each model. We'll be thinking about it for each model. The idea is to come up with a set of recommendations that will work, and will work realizing that it's sort of like probably in the case that nobody is necessarily even a pure example of any of these three models. Everybody is a hybrid to one extent or another. But if we do our recommendations right, hopefully we'll provide information that is useful to these organizations.

Continuing on, here's what the plan is. For each topic, we're going to try to create a common understanding of the topic. We're going to identify some questions, and try to develop, so it's the last issue is policy recommendation at an appropriate level. In other words, whether it's the technical level or the level of detail that is needed on the issues, so we may be involved in some high level things, but we may sometimes get into some fairly detailed issues. As you'll see in a minute, ONC has a contract with MITRE Corporation, so we have some people who will help us with meeting, planning, and facilitation, which is terrific. And so basically what we have is we're going to have more structured agendas with hopefully clear and attainable goals, as I just mentioned, meeting support and facilitation by MITRE using Web conferencing, and also MITRE is going to be giving us meeting minutes, which is a summary of the topics, questions, and decisions promptly after the meetings, and so that will also be very helpful to all of us.

The basic ground rules that some of this was reviewed before, but I want to go through these ground rules again, the ground rules for participation in the meetings. We ask that you do your best to participate in all meetings if at all possible, that you help us with adherence to the agenda and allotted time for each topic, and if you can't make a meeting, we certainly understand that, and if you could notify us in advance of an expected absence, that's really very much appreciated. Then what we can do is we can work with you to make sure that we can help you if you miss a meeting to stay up to date, so if you review the meeting summaries. You can contact either Deven or me or somebody at MITRE for clarifications.

We want to make sure that everyone is kept up to date with what is going on. Also, if you're missing a meeting, as it says in the middle, you should feel free to share thoughts or considerations on particular topics in advance because we will do our best to make sure that your opinions are heard. Again, we appreciate all the time you've put into this, and we're going to do everything we can to make sure that you have a chance to express your opinion on every single topic.

We are going to, as it says on the next slide, the first bullet, we are going to try to get consensus on developing the policy recommendations, but in the second bullet, if a consensus cannot be reached, we're going to report the status of the issue, and we may say the majority feels that X is what is happening, but there is a minority opinion that says Y is the right way to go. And so we will report the opinions. It's almost like my comments that I made offline before the meeting started about the Middle East where everybody knows what the other people's position is. Well, we want to make sure that we develop positions, and we actually will have done something very successful if we simply articulate sometimes two positions on a single issue or maybe more than two.

The other bullet that's very important to mention in terms of the ground rules is that once we agree on a recommendation, we're not going to revisit it, however, unless there's like a very clear consensus that the group wants to revisit it, and that could occur. I think, almost an example of a variation of what Rachel suggested, sometimes you get to another topic, and you realize that perhaps something you did previously was not – needed to be altered for one reason or another. But again, all the dissenting views presented after the tiger team discussion will also be noted, so if you missed a meeting, you can still present a dissenting view. So those are the ground rules.

What we want to do next is talk a little bit about how we're going to frame the discussion. Does anybody have any comments about the ground rules? Terrific. Deven, do you want to talk about how we're going to frame this discussion?

Deven McGraw - Center for Democracy & Technology – Director
Sure. We're going to begin again. Our goal here is to bring up a particular policy topic and then think about it in terms of some basic HIE exchange models out there, but ideally, again, we're striving for some

consistency in policy that governs data sharing, but with an acknowledgement that in some circumstances there are policies that might apply to particular models that are not needed or are universally shared across the models. And so we do have some three basic examples of health information exchange that we'll talk about with a recognition that the reality for any particular type of exchange is likely to, in many cases, be a mix of the models. But at least we will have a baseline to jump off from in our policy discussion.

There's also a need to be very clear of what we think the purpose of health information exchange ought to be in order to guide our recommendations. In part, some of this is about carving up this very big universe into smaller pieces in order to be able to have focused discussions and ideally come to resolution. This is, in many respects, is going to be hard, I think, for a lot of us because one topic reminds us of another, and things are very closely interrelated. But my sense in working with both the larger working group and this tiger team over the last several months is if we cannot engage this in somewhat bite sized pieces, we are going to struggle with coming to recommendations and, as Paul noted, it doesn't mean that as we expand the universe of purposes of exchange and think about other ways that data can be shared beyond the sort of original confined universe that we begin with, that we might want to reassess the recommendations that we come to at the beginning. And there's nothing wrong with that, but if we don't start with something that we can bite off and chew and come up with some concrete recommendations for, we'll probably just spend these calls talking ourselves to death, and that's not a good use of time for any of us.

So we, in talking with Joy Pritts, agreed to confine our discussion about policies for health information exchange, to the exchange that's called for in stage one of the meaningful use. Again, that's the proposed criteria because we don't have final criteria yet. We have to go with what we know. And so, therefore, we think that we should be focusing our policy discussions on the exchange of information for care coordination and treatment of a patient for the quality reporting that's called for under the meaningful use proposed criteria and for the public health reporting that's called for in those criteria.

Again, we know that that is far from the universe of health information exchange. And so certainly I think that from a policy, from a long-term policy standpoint, the conversations cannot end there. And so one, but not the only thing that's not included in that sort of bucket of purposes of exchange is research. Payment is another one. It's not as though those are not important considerations. But we want to start with the exchange that's required of stage one for meaningful use and build from there, and so we think – I'm trying to remember what the 80/20 rule is, Paul.

Paul Egerman – eScription – CEO
The issue with the 80/20 rule is simply to say that we do have – we're operating on a clock. We have a timeframe, and so it is most likely that we will be addressing the issues that are most prominent. We may not get to everything, so even when you look at these three issues, coordination of care, quality reporting, and public health reporting, it's really the first one, coordination of care, that will probably dominate our discussions.

Deven McGraw - Center for Democracy & Technology – Director
Yes.

Paul Egerman – eScription – CEO
And so the 80/20 rule is, we're going to focus on the things where we think the most issues are right now, and that means we may not get everything done.

Deven McGraw - Center for Democracy & Technology – Director

Thank you. We do have, in the following slides, some basic health information exchange models. Again, it's entirely likely, and we acknowledge that there are a number of models out there that are hybrids of one or more of these. Directed exchange, peer-to-peer, which has been the focus of our conversations to date, a federated exchange model involving a hub of some sort, and then what we're calling a centralized exchange model that others might call a database model. The description of these models, which MITRE helped us out with, came from the state HIE toolkit that was developed by ONC quite recently in order to try to maintain some consistency in the way that these models are described and discussed. And again, the scenarios basically are focused on providers and suppliers of healthcare because our schedule has us focusing on provider and supplier level exchange with patient access and exchange issues coming up later in our conversations.

Neil Calman - Institute for Family Health - President & Cofounder
This is Neil. I appreciate the fact that we've sort of parked the patient access issues, but at least for me, it would be helpful to know how that works in these different models and how the public health reporting works in the different models because I think even though we're not going to be discussing them primarily, it's still important to know how they fit in, in order to sort of contemplate what the different models, what future implications those models have.

Deven McGraw - Center for Democracy & Technology – Director
I think we'll have to fill that in because I think that, and I don't want to spend too much time on it, Neil, because if we start getting into policy discussions about patient access, it defers our focus from the provider exchange issues that we want to focus on first. It doesn't mean we won't get to the patient access issues, but so noted. We can try to fill that in for these models.

Neil Calman - Institute for Family Health - President & Cofounder
I guess I'm just saying that because you're not going to have different models for different types of access, so if you're going to contemplate which kinds of models we're going to support, we sort of need to know how they work in total, not just how they work in this one, for provider-to-provider exchange. At least from my point of view, that's all I'll say.

Paul Egerman – eScription – CEO
That's a great observation, Neil. I would also make the observation, if you looked at all the issues we put on the parking lot, so far at least one person has wanted to talk about every one of those issues as part of our process, and so it's just an observation that Deven, Joy, and I need to think through because we certainly hear that for different reasons, different people have specific interests in those areas.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
While you're recording that list of different reasons and different interests—

Deven McGraw - Center for Democracy & Technology – Director
Stick another one on there.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Yes. I noticed that when you compare this to the URL that points to the state toolkit, distribution by a portal media was omitted. I assume that is related to the decision to focus on provider-to-provider. I just would observe that a meaningful use requirement for providers is to provide electronic copies of healthcare information to patients, so this one may come up at a give point in time.

Deven McGraw - Center for Democracy & Technology – Director
They will. Yes, and it should, Wes. That's a good point.

Gayle Harrell – Florida – Former State Legislator
This is Gayle. I'd also like to add, there's a great deal of concern among patients and among providers about what happens to your information when it goes to insurers and payers and what those privacy concerns are, especially when you get into DNA and to testing and things of that sort. What's the game plan for that?

Deven McGraw - Center for Democracy & Technology – Director
It's a good question. We have deferred that discussion, but we haven't calendared it, and we need to do that.

Gayle Harrell – Florida – Former State Legislator
Absolutely.

Paul Egerman – eScription – CEO
Yes. Could you give me a title of that topic, Gayle? What would you call that? Is that payer privacy issues, or is that…?

Gayle Harrell – Florida – Former State Legislator
It's an issue with what happens when payers have the PHI and what happens, what decisions they're making with it, how much access do they have to it.

Paul Egerman – eScription – CEO
Payer use of PHI, is that a good…? I just want to put something down on the list to make sure that I capture it correctly.

Gayle Harrell – Florida – Former State Legislator
Correct. Payer use of PHI.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
It really falls more broadly into secondary use, use that goes beyond the treatment, planning, and operations perhaps.

Gayle Harrell – Florida – Former State Legislator
And what is their ability to access that and use it, use it, sell it?

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Can I make a suggestion we change that slightly? This is John Houston. It's disclosures for payment purposes rather than just disclosures to payers.

Gayle Harrell – Florida – Former State Legislator
Okay, for payment purposes.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
There might be a slight distinction between those two.

Paul Egerman – eScription – CEO
Tell you what we'll do is we'll try to write it up, and if we don't quite get it right, make sure you send us an e-mail, but I think we understand the basic concern, which is certainly a very valid one, and so we should

put that somewhere, if we don't have it on the calendar, put it on the parking lot so that we make sure we don't forget it.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
This is John Houston. One other comment: Some people would argue that that use is more important than uses for quality and other purposes.

Gayle Harrell – Florida – Former State Legislator
I would absolutely agree with you, John.

Deven McGraw - Center for Democracy & Technology – Director
Well, and I'm not sure that important is the right adjective. Maybe for many people, it is of more concern. But I think that we are focusing on the subset of exchange that's required for meaningful use because that's consistent with programmatically where the dollars are going.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
I understand that. I just think that some people will look at that, and that is a comment you will receive back, and I thought it would be important to at least put it on the table.

Deven McGraw - Center for Democracy & Technology – Director
Yes.

Paul Egerman – eScription – CEO
Very helpful.

Gayle Harrell – Florida – Former State Legislator
I would also say that when you justify what you're talking about in state one meaningful use, if you want to get there and have the public accept that exchange for meaningful use, we had better address this whole issue, and I think it's extremely important.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
This is Carol. I think, in our work, in the common framework, there are two policy areas that we broke this out into. One is, as was said, the collection, use, and disclosure of information, those general policies, but the second is really about discrimination and compelled disclosures, which I think is the issue that is being referred to as a significant area of concern.

Paul Egerman – eScription – CEO
Thank you. Very helpful.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
This is David. I want to throw in another comment just for the record. As a technologist, I appreciate the focus on architecture and technology as sort of one axis of analysis of these policy questions, but I would argue that it's a multidimensional problem and that we might also want to consider some other organizing axes that may affect policy even more than the technology choices would. For example, where or what's the basis of the aggregation of the data. Is it regional? Is it state? Is it cross state focused on the person instead of the state?

Who controls the data? Is it consumer controlled? Is it stakeholder controlled? Is it state controlled, etc.? There are a number of other analysis points that would have as much bearing on policy decisions as technology choices, which, by the way, I'll second the notion that these three are an inadequate spanning set for the current approaches that are being used in the real world. I just want to register that thought that we might want to consider the other analysis points from when we dive into these policy choices.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
Yes. I agree with that. I think the level of aggregation question is an extremely important one, but I have a question since these are the three models that are articulated in the state HIE toolkit on level of aggregation. Has ONC said from a policy perspective that the state level centralized database of information is an acceptable model from a policy perspective? In other words, is that already a determination that's been made?

Joy Pritts – ONC – Chief Privacy Officer
It is my understanding, not having been here when the request for proposal first went out for these grants, but no model of exchange has – the states are not precluded from using any model of exchange.

Gayle Harrell – Florida – Former State Legislator
I want to remind everybody, we have a Tenth Amendment to the Constitution. Remember that, Paul?

Paul Egerman – eScription – CEO
Yes. Absolutely, and I appreciate that, but picking up on what Joy said, my understanding is ONC is allowing all models and a centralized model. I actually am getting some feedback that some people really like the centralized model. They think that that's the way to go. And so there are all three models, and they may not be perfect descriptions, but they are rough descriptions of things that are currently happening. I'm wondering if what we really should be doing in this discussion is having Deven go on through the slides and actually go through what the description of the models are that comes from the toolkit.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
I just want to make a point of clarification to reiterate David McCallie's point, which is the level of aggregation in a centralized model is a very important axis on which a lot of these policies will depend. My question was specifically about a state level, central aggregation of PHI. Thank you.

Paul Egerman – eScription – CEO
That's an excellent observation that we need to add to our list, so I appreciate that, Carol and David. Deven, can…?

Deven McGraw - Center for Democracy & Technology – Director
Yes, I heard another voice in the background. It sounded like John.

Micky Tripathi - Massachusetts eHealth Collaborative - President & CEO
No, this is Micky. No, I was actually going to cast a vote in favor of using this structure. I think there are all sorts of variations here, but we need a place to start, and I think a lot of the threshold policy questions that are going to come in play here are going to be at least captured for first pass purposes by these three models.

Paul Egerman – eScription – CEO
It's good to hear from you, Micky. I guess you weren't there for the roll call, but I'm glad you were able to join the call, so that's great.

Judy Faulkner – Epic Systems – Founder

This is Judy….

<u>Deven McGraw - Center for Democracy & Technology – Director</u>
Keep in mind, again, that we are discussing policy that we want to apply across a range of models or to be almost model neural, except where we want to respond to particular aspects that may be characteristic of a model. I'm going to go ahead and go through these models, but fully recognizing, again, that these are not the exclusive models. They are not necessarily wholly representative of what's out there, but it is essentially, as Micky said, it's a place to start. There certainly can be issued raised when we get to policy discussions on the next issue that's teed up for our call, which we'll get really more into the meat of on our next phone call, which is collection, use, and disclosure limits, including those on data reuse and retention. But again, just to sort of level set the discussion and have some awareness of some core basic models that are out there, and that ONC has put out there in the toolkit, that's really the purpose of going through these.

The first one, being again the peer-to-peer or directed model, some of the – and a sample scenario is where a provider sends a patient record to a specialist, and some of the features in this example are that typically a user has to know where to send the information. We've talked about this in terms of provider to known provider, but there still needs to be a digital way of getting that information from point A to point B. There's no central data server. But typically or in some models, a directory server of providers, not patients, can be used to facilitate the communications.

Each system communicates on an as-needed basis with other systems. The data is displayed within each user's local system or stored locally. The features can include standards for communication, both in terms of data format, message types, and communication techniques, and it can support real time messaging or batch communications depending on the capabilities of the systems that are involved in the exchange.

In the next model, which is labeled the federated model, the sample scenario for this is that the provider sends a request to a hub for patient lab data. The hub identifies the labs with the possible matches for the patient. Patient match is confirmed, and the lab data is then routed back to the provider via the hub, so in this, one of the example features is a central hub that's operated by regional authority, either public or private. The hub actually does have a master index of patients that are contained in all the systems that are participating, but that master index does not contain any clinical records.

The participating systems are flagged in the index as possessing data for a particular patient. System queries, the hub to identify where parts of the patient's record exists elsewhere, and then either queries those systems directly or accesses patient record through a central hub application. Community-wide standards for communications, those for data formats, message types, and communication techniques.

And then the last basic model is called the centralized model where the sample scenario is that the provider, lab, and imaging center all send patient information to a central repository. Example features include there's a central database operated by the regional authority, which contains complete, consolidated record of all people and their medical data, sometimes referred to as a union catalog. I must admit, I haven't heard that term, but that's not my area of expertise. Systems are required to periodically supply data in order to keep the central database populated and current. Again, the communications use standards and can support real time messaging or batch communications depending on the capabilities of the participating systems.

We have a little time to argue about these models now, which I'm sure that we will. But again, those are presented in their basics with the acknowledgement that in many cases states or national systems may be some hybrid of one or more of these.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
This is David. I'll start.

Deven McGraw - Center for Democracy & Technology – Director
Go ahead, David.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
I think Wes made this point earlier, but I'll just reiterate it that in many of the real world examples, there's a mixing of these models. In particular, one common, although somewhat technologically illogical model is the notion of a federated model by organization of the data, but when in fact all of the data actually exists in a centralized location. That's a common variation.

Deven McGraw - Center for Democracy & Technology – Director
What does that look like, David? Describe that.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
Each supplier of the data agrees to upload data into a centralized store that contains just their data. And then the hub, which is collocated physically in the same facility, queries these local copies of the source's data. What you get from that, the benefit, and this is the Indianapolis model, for example. What typically happens is when the data is uploaded from the source, it's transformed into a canonical format, and then it's stored in a database that doesn't mingle the data with anybody else's data, but it's now all locally ready to be queried with fiber optic connections and high speed, and it's all been transformed to canonical form.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
Right. This is essentially leveraging the efficiency of a data center, if you will, but the data is not logically commingled. It's physically centralized, but it is not logically commingled, so there is no one single database that contained all of it.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
But I would note, just totally in passing in my e-mail this morning was an announcement about a recent report from OCR about data breaches that came out over the weekend summarizing the ARRA, HITECH, mandated reporting of data breaches. And the vast majority of the data breach, I'd say vast majority, the majority of the breaches occurred with physical theft of devices and hardware and servers and things. So centralization physically has as many risks and issues as centralization logically, so just point out that the real world is more complicated than these three models.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Yes. We've often called this the edge proxy model, and I don't think it serves to debate this. If it did serve, I would probably take David on, on this point, but I think….

Paul Egerman – eScription – CEO
…This is Paul. Because the variation of doing that, what you call the Indianapolis model, I'm familiar with one model where I think this is maybe what you meant, Wes, by the edge proxy where a copy of the database is maintained actually at what's called the edge, but by the individual provider.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Yes….

Paul Egerman – eScription – CEO
So it still operates in a federated way, but the provider never loses control of the data. They simply keep a copy of the data in their sort of canonical, standardized format to make it convenient so that they can run their own internal formats that are maybe different.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Right, and I think that what's happened is it started out that way increasingly, as the data sources, whose primary concern was commercial use of commingled data, such as finding out which orthopedists were doing the most hip replacements and making them an offer and things like that. Gradually, they've moved over towards technological safeguards that protect their data, but physically citing at the central. At any rate, I don't know that the notion of other than in technological discussions about federated versus centralized. I don't know that it matters much. I mean, it's easier under the control of the source, or it's under control of the hub.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
Well, it does matter in this way, Wes, and I think this is something that we learned over time, which is that if everything is completely centralized, then all the participants have to agree to a uniform set of policies because the data is managed as one. If they are not, however, and the provider of the data has some control over the data, people can choose to implement different policies, for instance, within their own regional exchange for access to information or what have you. They can choose to implement some of those policies differently, and if that's not an option, then there has to be one universal set of policies that govern the data. So it actually does have significant policy implications.

Deven McGraw - Center for Democracy & Technology – Director
Yes.

Micky Tripathi - Massachusetts eHealth Collaborative - President & CEO
This is Micky. Maybe I'm touching on a different point, but that's not related to the question of where the physical store is, right? That's a question of central….

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
It is not. It is not, Micky. It is not. It is related to whether or not the data is managed in a logically centralized way.

Paul Egerman – eScription – CEO
Yes.

Micky Tripathi - Massachusetts eHealth Collaborative - President & CEO
Right. It's how much orchestration you want around it, but whether it's like Indianapolis or federated, meaning physically, like NEHEN where there are gateways at each host institution.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
Right.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
So I think we agree, if I understood this all, we agree that federated versus centralized in terms of logical ownership is a significant variable. Proxy is not a policy factor, or did I misstate what you said, Carol?

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
I'm not sure I tracked that. Could you say that again?

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Well, I'm just wondering what we're talking about.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Right. Do we think there's a difference between a single store, which I think is kind of the lay understanding of a central repository versus federated stores that are orchestrated in some way? Do we think there's a policy difference between those two?

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
I don't.

Paul Egerman – eScription – CEO
Let me try to respond to it, Micky, a different way is by saying we need to make a distinction between privacy and security. When you talk about security issues, if there's a centralized store, the security issues are different than if there's not a centralized store. But the privacy issues, if it appears to the user, in other words, if it appears to the user that the data is aggregated together from multiple sources, it may not be relevant from a privacy standpoint where the data is located.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
I like that. That's a good point, Paul.

Gayle Harrell – Florida – Former State Legislator
It brings up very significant policy considerations that really go across both aspects of it. And patients look at things. They don't segment into privacy and security. They have concerns whenever you have aggregation, whether it's in several different lock boxes, or whether it's in one lock box. They have the same concerns when it is aggregated.

Paul Egerman – eScription – CEO
That's correct, Gayle. What I'm suggesting that maybe this is what you're saying is, from a privacy standpoint, the physical location of the data is not important. We need to look at these issues the way the patient would look at it in terms of who is getting access to my data. What are they using it for?

David McCallie – Cerner Corporation – Vice President of Medical Informatics
Yes.

Paul Egerman – eScription – CEO
Those are the privacy issues. The physical location does have an impact on some interesting security issues, but those are actually kind of boring issues. In other words, we know how to solve those things. The problem is nobody does it right. But that's my observation, so if you get back to the three models that are being presented here, I still believe, from the standpoint of privacy policy, this is a good way to think about it. In other words, you might think about, you know, we might look at the centralized model. Instead of thinking of a centralized database, maybe we need to rename it like an aggregated database or an aggregated view of the data. In other words, you can see the data from multiple sources and not really think about the database, but just the fact that somehow data is being brought together. Maybe that's the way to respond to the issues that you're raising, David, also about statewide aggregation. The third thing is, we call it centralized. It's better to say aggregated.

Deven McGraw - Center for Democracy & Technology – Director
I think it's both, and this gets back to, I think, the way that David was talking about sort of conceptualizing the models in ways that where the differences matter from a policy standpoint, and so it's not just that centralized is aggregating multiple sources of data in one, but it's also central control, right?

David McCallie – Cerner Corporation – Vice President of Medical Informatics
Yes. I think, I mean, this is David. That was clearly one of the angles or one of the axis of analysis that I was proposing is who controls what span of data. Intuition tells you that the more you centralize, the more there's a risk of a privacy breach, but it may turn out that if the control is set up properly, there's actually a reduction in possibility of privacy breaches. Then, of course, as Paul pointed out, the security breach risk is a different axis and may in fact go in the opposite direction of the privacy breach issues. And all these are going to be tradeoffs.

Paul Egerman – eScription – CEO
Right.

Judy Faulkner – Epic Systems – Founder
This is Judy. I've been on for a while. I'm thinking of it from how it works with the patient and the provider and, Deven, kick me out if I'm on the wrong topic right now, but if one of the provider – one of the provider organizations was talking to me recently about this. If a patient shows up at their facility, and they use direct exchange, okay, that's one way. If they use the RHIO that is being planned in their state, that's another way.

I have two questions. One is, if – and the third thing is, if the patient shows up from, say, Texas, and they're in Chicago, how will they know what to do in each case, number one? Is it required that they always be able to do it? Then pay wise, they were very concerned about how they pay for everything if it is a requirement because the costs of the RHIO were coming out to be – they were between almost $200,000 to $800,000, I think, a year. As we talk about these, how do we explain them to the providers who have to deal with that patient who shows up? Kick me out if it's the wrong thing, but I'm trying to map….

Deven McGraw - Center for Democracy & Technology – Director
It's a little bit of policy by example.

Judy Faulkner – Epic Systems – Founder
Yes.

Deven McGraw - Center for Democracy & Technology – Director
Which I think we need to try to think about your questions, Judy, in the context of some broader policy questions. I feel like I'm in bureaucratic speak, but you're asking us to drill down at this. You're asking for answers that, one, we haven't developed yet from a policy context.

Judy Faulkner – Epic Systems – Founder
Then should we be saying there's only three models if we don't…?

Deven McGraw - Center for Democracy & Technology – Director
We're not saying there are only three models, Judy. We never said that.

Judy Faulkner – Epic Systems – Founder

Okay. I thought you did.

Deven McGraw - Center for Democracy & Technology – Director
No.

Paul Egerman – eScription – CEO
No. What we're saying, Judy, is we're using these three models to help guide our decision-making and our discussions.

Judy Faulkner – Epic Systems – Founder
Okay. I know you said there would be mixes of them all.

Paul Egerman – eScription – CEO
But there might be hybrids, and we sort of need to understand the three fundamental models.

Judy Faulkner – Epic Systems – Founder
But couldn't there be others than this too?

Paul Egerman – eScription – CEO
There could be others.

Judy Faulkner – Epic Systems – Founder
Then I'm okay.

Paul Egerman – eScription – CEO
And so that's the case. Getting back to the centralized model, to sort of pick up on the prior discussion, I almost wonder if our understanding of the centralized model, because I'm looking at the slide again. It really talks about central database is that somehow we need to retile this. It's really aggregated. It's an aggregation of data with a centralized level of control is really the theme because it may not be a central database was the message that we got.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
This is David again, just to point out another variation where these things blur together. In the purist implementation of the federated model where you try to minimize the amount of central information, physically central or logically central, and when you try to minimize it, you're still, to the degree that it's useful to the clinicians, you will in fact denormalize some significant PHI up into that central record locator service. You will have, to make it queryable without an immense amount of physician time, you're going to put information up there around what kind of tests you're querying for, what kind of radiology procedures and so forth. Even in a federated model where you push all the information as far out to the edge as possible, you will end up with PHI in the center, so it's not clean.

Deven McGraw - Center for Democracy & Technology – Director
I actually disagree with that, David.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
Pardon?

Deven McGraw - Center for Democracy & Technology – Director
I mean, I think that's a policy choice.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
I'm just telling you….

Deven McGraw - Center for Democracy & Technology – Director
Now how much clinical or PHI needs to be exposed in the index in order to locate a patient's record. That's not a foregone conclusion. In fact, I would argue that's a policy choice that we've got to take on.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
My point is a little bit that at least in our experience that if you look at XDS, which is the model that is recommended by NHIN standards, HITSP standards, there is, in the registry, the central resource, the registry, a fair amount of PHI by default. If you use the IHE recommendations off the shelf, you can do queries for type of document and time range and clinician in a variety of other ways, which reveal a fair amount of clinical information about the patient. The actual documents aren't stored there. That's true. The deep data is not, but this substantial exposure of clinical information in an off the shelf XDS model.

Paul Egerman – eScription – CEO
Just to be clear on this, what David is suggesting, because I'm not sure if everyone understands is, in this kind of a federated model, this index could include information sort of like saying for this particular patient, there are lab results that occur during this timeframe.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
Correct.

Paul Egerman – eScription – CEO
It doesn't necessarily say what the lab results are or even what tests were, but just that this is the kind of data and possibly even the timeframe that exists for this patient at this location.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
And if it's something like a mammogram, the actual mammogram would be listed in the registry.

Paul Egerman – eScription – CEO
You could see that someone had a specific test sometimes.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
Yes.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
I think, David, that you've beautifully articulated the point that I've been trying to make, which is, sometimes the selection of standards in fact make policy determination. The way … gets implemented makes policy determinations about what information is exposed and when. I do think this is a matter of policy. If left to sort of, you know, people to decide, it may get made by the selection of standards and technologies. But it is fundamentally an issue of policy.

Paul Egerman – eScription – CEO
Maybe, Carol, but the decision of the policy committee was, I mean, to speak to the example that David gave, if the policy committee members were here, they'd say there's nothing wrong with what was just described as long as there's reasonable utility that comes from it.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

No. I disagree. I think what you're saying now is about intermediaries, and what I'm suggesting is about the standard. This has nothing to do with intermediaries. You could expose no PHI and information exchange standard and yet sign up with an intermediary to expose it all because you need some value added service. These are separate issues that we should not be mixing. This is really a question of the standard and the technology that gets used, and what inherently requires not about intermediaries or other services, which people will always choose to use and will always need to have appropriate safeguards in place.

Paul Egerman – eScription – CEO
Yes, but if I were to expand on what the policy committee decided, they decided that….

Joy Pritts – ONC – Chief Privacy Officer
Paul, this is Joy. I'm going to jump in here because it's 11:30. I think this is an interesting discussion, but you're delving into the substance a little bit too much here. I'd like to finish, if we could, because it's been very helpful in highlighting some of these models and issues. I think that the issue that was just raised here is that there is a policy issue about, in a federated model, about how much PHI is exposed in an index. We don't have to discuss whether that's a good thing, bad thing, or what the policy committee would think about it. There's an issue that needs to be addressed.

Deven McGraw - Center for Democracy & Technology – Director
It wasn't squarely presented to the committee in that way.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
I agree.

Joy Pritts – ONC – Chief Privacy Officer
No.

Gayle Harrell – Florida – Former State Legislator
Also, this is Gayle. I'd like to add that there are also audit trails and, in a federated model, there are audit trails that have to be maintained, and that is then held for a length of time as to who accesses what and whether that information came from an abortion clinic, certainly PHI, just in the title of the institution it's coming from. So audit trails need to be addressed in that whole thing.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
Agreed.

Micky Tripathi - Massachusetts eHealth Collaborative - President & CEO
This is Micky. Paul, can I ask a clarifying question then? Given this discussion, which I, and I agree with your recasting of centralized model of being more about, you know, sort of almost about aggregation or highly orchestrated, centralized kind of approach. What's the line? Given the degree of orchestration is really a continuous variable here, what's the line that we're going to try to use to demarcate centralized from federated?

Joy Pritts – ONC – Chief Privacy Officer
This is Joy. I don't know that we really have to demarcate it, as long as when we're having the discussions going forward that we recognize that there is this continuum and that, when you're making policy recommendation, you're trying to make sure that you're covering the continuum from the situation where the hub or whatever you want to call it has no control over the data, or that the provider has most of the control over the data to the part where the centralized unit has most of the control over the data.

Paul Egerman – eScription – CEO
Yes, and I'm glad you said that, Joy, because I didn't know the answer to Micky's question, so that was a great answer. It doesn't appear to be the issue….

Joy Pritts – ONC – Chief Privacy Officer
But let me ask if that makes sense to people. Do you feel like you need to really, I mean, the reason we've had these up here is we wanted to make sure we kind of cover the bases. We understand that there are differences in some of these. For example, the index that we were just speaking about, and the federated model may be one of those. Those are the reasons for having at least the models, even in straw man. Let's make sure we cover the bases. Is there a need to really finally articulate the distinction between the two or three, particularly given the hybrid models?

Deven McGraw - Center for Democracy & Technology – Director
I don't think there is, Joy, and I think that we have to explore those distinctions where it's necessary to do so in the context of a particular policy question because otherwise I fear that we'll spend a lot of time arguing about where the line gets drawn. I think we'd have very clear ends in terms of particularly on the issues of aggregation and control with no aggregation and control by the record holder on one end, high aggregation and centralized control on the other, and a whole bunch of hybrid in the middle.

Paul Egerman – eScription – CEO
I agree, Deven, because I think this is a great discussion because we have sort of a sense of these three models, and Micky's question is a good question because it shows that it's hard to know exactly where one model ends and another model begins sometimes. The real issue is how do we apply this sort of background knowledge then to the issues that we have? I'm wondering if this might be a good segue to introduce what some of these questions are that we want to talk about in our next meeting regarding data collection and reuse.

Deven McGraw - Center for Democracy & Technology – Director
Sure. Here's the topic for our conversation on the 9th, which is Friday. A mere few days from here, our collection, use, and disclosure limits of which the issue of data reuse and retention by intermediaries or third party service providers is nested within that, and we have – what we're going to do is distribute to you a set of questions for you to noodle on and provide some feedback on over the next few days in preparation for Friday because, I think, ideally, in advance of the discussion on Friday, we would want to have some sort of straw proposals based on some interim feedback that we get from all of you as tiger team members in order to help guide our discussion on Friday.

The two central questions of which there are some sub-questions nested within, but we'll be sending this to you. You actually have it as a download available on the Web site. It's the download that starts, again, see the left-hand side of your screen if you're online now. What limits should – that's the amount that I can see on my screen … but it's the two questions are, what limits should be placed on the collection, use, and disclosure of PHI by providers? The second question is, what limits should be placed on the use disclosure and retention of PHI by third party service providers, also known as intermediaries? Does this include potentially limits on what the exchange itself, which we have come to call an HIO at the policy committee, or a database in models where those are used? We're going to distribute this by e-mail so that you have it, but essentially we want to get your feedback on those.

Keep in mind that we have already said that we're going to focus on the data exchange transactions that are necessary for state one of meaningful use for providers, deferring to later use of getting patients access to their data, trying again to sort of carve out the universe into bite sized chunks, so we're starting with providers, and we're starting with those purposes for which data needs to be exchanged under stage one. There's stuff that's not on the table, but if we can make progress on what's on the table, then we can more quickly get to these other issues, which I agree are very important, including the payment issue, including the issue of sharing information with patients. That's the sort of overarching plan. To the extent that you think the limits ought to be slightly, the policy ought to be slightly different in a particular exchange model such as one that is highly aggregated with central control or one that is characterized by neither of those, then you should say so.

Joy Pritts – ONC – Chief Privacy Officer
Deven, this is Joy. I'd like to jump in here just for a second and say that I think that in order for this group not to be reinventing the wheel, it's helpful to keep in mind that we do have the HIPAA privacy rule, and to the extent that—

Deven McGraw - Center for Democracy & Technology – Director
We have what? No. I'm just kidding. Just kidding. Go ahead, Joy.

Joy Pritts – ONC – Chief Privacy Officer
To the extent that the group identifies gaps in that rule or things that they believe that may not adequately address the models that are developing, those are all fine issues for this group to be considering, but what we really don't need to do is totally reinvent the wheel here.

Deven McGraw - Center for Democracy & Technology – Director
Right.

Paul Egerman – eScription – CEO
Are these the right questions for us to be addressing on this topic: data collection and reuse and disclosure limits?

Deven McGraw - Center for Democracy & Technology – Director
Who are you asking?

Paul Egerman – eScription – CEO
Everybody. I'm asking Joy, but everybody. Are these the right questions?

David McCallie – Cerner Corporation – Vice President of Medical Informatics
Do I recall that the consent question comes up later, and we should defer that, or do we add that…?

Paul Egerman – eScription – CEO
Yes, the consent is going to be – in the sequence, consent happens next week after we've figured out collection, use, and disclosure limits.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
Okay.

Deven McGraw - Center for Democracy & Technology – Director
Yes, and that was purposeful, David, because in our larger workgroup, we really struggled a bit with addressing the issue of consent without addressing the circumstances under which we were asking patients to consent or not consent. And so, rather than starting with patient management of information and provider records, we want to start with what are the rules for which information can be exchanged by

… under what circumstances, and then you can layer. Not that it's easy ever to get the question of consent, but at least you have some idea of what you're asking patients to opt into or opt out of.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
So when we think about the questions that are in front of us, do we assume that consent has been either granted or is irrelevant? How do we factor consent out of how we answer these questions?

Deven McGraw - Center for Democracy & Technology – Director
I think you just assume current law applies, which is HIPAA plus any state law requirements on top of that.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
Okay.

Micky Tripathi - Massachusetts eHealth Collaborative - President & CEO
If I'm understanding this, to the extent that we were just talking about that there is this spectrum of orchestration, which is really about degrees of control, it seems to me that this collection, use, disclosure limits, all of that are in a way defining what is that spectrum of control, correct, at least from the provider, from the source system perspective.

Paul Egerman – eScription – CEO
That's a good observation, Micky. My question is, are we asking the right questions? In other words, is there another way we should be phrasing these questions to get at the very issue you just raised?

Deven McGraw - Center for Democracy & Technology – Director
I think it's a little hard for folks without the paper in front.

Paul Egerman – eScription – CEO
Right.

Deven McGraw - Center for Democracy & Technology – Director
You and I have the benefit of having it in front of us. Maybe we ought to allow people to chime in on the questions, as well as the answers.

Paul Egerman – eScription – CEO
Yes. Maybe what we should do, if this works for everybody, is we'll e-mail out the questions, and the first issue is did we get the questions right. Are there other questions that we need to address? The next issue is, well, what are the answers?

Deven McGraw - Center for Democracy & Technology – Director
Right.

Paul Egerman – eScription – CEO
But one of the things I'm thinking of is do we want to try to tackle some of the issues that Gayle raised about payer use for PHI or at least … stick with coordination of care right now. Th payer use of PHI is interesting, but it's not stage one of meaningful use.

Deven McGraw - Center for Democracy & Technology – Director
Yes. I also want folks to know that the questions did not come out of the air. I mean, it was essentially taking the nationwide framework document that ONC developed a couple of years ago, and that was

endorsed in the strategic plan, and also to the extent that very early on, the tiger team helped to populate some additional questions and issues on that framework document that we circulated for a couple of weeks. Paul and I used those in coming up with the questions to put before you for these meetings. Just so you know, no good deed – good deeds get rewarded here. We have not – that document did not go into the trash. We're using it to come up with … that we're asking you all for specific feedback on in order to hone our policy recommendations with a bit more specificity.

Micky Tripathi - Massachusetts eHealth Collaborative - President & CEO
Right. I wonder if it's useful, and I'm just thinking out loud here. This is Micky again. Sorry. To think of sort of, there's provider control or source system control, and then there's patient control, and they're obviously related. A source system can't give a patient a degree of control that they have seeded. On the other hand they, by law, shouldn't be feeding control that is supposed to be in the patient's hands.

Paul Egerman – eScription – CEO
That's a valuable observation.

Deven McGraw - Center for Democracy & Technology – Director
Yes. I think, for this initial set of recommendations, where the law gives control to the patient, we should assume that.

Micky Tripathi - Massachusetts eHealth Collaborative - President & CEO
Right.

Paul Egerman – eScription – CEO
We will e-mail out the questions and ask you again to first decide if there are additional questions you think we should answer, but then also what we'd like you to do would be to start formulating in your own minds what you think the answer to these questions are and even e-mailing everybody else. Wouldn't it be great if we had some e-mail discussion going on in advance of our next meeting so that people have a chance to think through some of these issues in advance and help formulate opinions?

Our next meeting is Friday, July 9th, at 10:00. Before we open it up to public comment, did you have anything else you wanted to say, Deven?

Deven McGraw - Center for Democracy & Technology – Director
No.

Paul Egerman – eScription – CEO
Anybody else have any other comments they want to make? Do you have any comments, Joy, anything…?

Joy Pritts – ONC – Chief Privacy Officer
No.

Paul Egerman – eScription – CEO
Okay. If it's okay, Judy, why don't we open the lines for public comment?

Judy Sparrow – Office of the National Coordinator – Executive Director
Sure. The public will be invited to make any public comments. Just a reminder to state your name, organization, and keep your comments to two minutes. Operator, can you please see if there are any public comments? Paul, I'll e-mail out those questions in just a moment.

Operator
We do not have any comments at this time.

Judy Sparrow – Office of the National Coordinator – Executive Director
Great. Thank you.

Paul Egerman – eScription – CEO
Yes. Thank you very much. Let me, again, thank all the members of the tiger team for your dedication. The first thing after a long weekend, participating in the discussion, I thought we had a terrific discussion today. It laid the groundwork for even better discussions to come. I also, of course, want to thank Joy Pritts and Judy Sparrow and the entire team at ONC.

Deven McGraw - Center for Democracy & Technology – Director
And MITRE.

Paul Egerman – eScription – CEO
And, absolutely, the people at MITRE who are doing a terrific job, so thank you very much to the entire MITRE team. Thank you. Talk to you on Friday.

Gayle Harrell – Florida – Former State Legislator
All right. Bye.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Thanks, Paul and Deven.

Public Comment Received During the Meeting

1. Please consider sensitive data and data segmentation in your discussion of policies for central vs local control over distribution of information. Example: the meaningful use rule requires aggregation of prescription drug information about a patient. But if information came from a substance abuse program, redisclosure may be prohibited without consent. Does the medication information merge into the recipient record, to be disclosed per ordinary procedure? Is there a need to "tag" the 42 CFR Part 2 data?

3. I am hearing some members delving into the procedures rather than keeping at the policy levels.